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Overcoming limitations of tuberculosis information systems: researcher and clinician perspectives

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Setting: Tuberculosis (TB) diagnosis and treatment requires patients to have multiple encounters with health care systems and the different stakeholders who play a role in curing them to coordinate their efforts. To optimize this process, high-quality, readily available data are required. Data systems to facilitate these linkages are a neglected priority which, if weak, fundamentally undermine TB control interventions.

Objective: To describe lessons learnt from the use of programmatic data for TB patient care and research.

Design: We did a survey of researcher and clinical provider experiences with information systems and developed a tiered approach to addressing frequently reported barriers to high-quality care.

Results: Unreliable linkages, incomplete data, lack of a reliable unique patient identifier, and lack of data management expertise were the most important data-related barriers to high-quality patient care and research. We propose the creation of health service delivery environments that facilitate, prioritize, and evaluate high-quality data entry during patient or specimen registration.

Conclusion: An integrated approach, focused on high-quality data, and centered on unique patient identification will form the foundation for linkages across health systems that reduce patient management errors, bolster surveillance, and enhance the quality of research based on programmatic data.

Despite diagnostic innovations, improved access to new and repurposed medications, and efforts to shorten treatment duration, tuberculosis (TB) remains the leading infectious cause of death worldwide.[1] Many care providers and researchers in high TB burden settings give vivid accounts of how flawed patient medical record data impair their ability to provide high-quality care and make an impact. These limitations undermine advances made in the global fight to end TB.[2] Reliable, integrated data systems would improve patient care, readily expose gaps in the care cascade, and enhance research based on programmatic data.

The World Health Organization (WHO) End TB Strategy stresses the importance of strong data systems via coordinated, context-specific approaches that prioritize the use and improvement of existing systems where possible.[2,3] In our experience, however, existing data structures and systems are inadequate and chronically underfunded, with limitations that are frequently not readily apparent to patients, providers, and researchers. Although many studies assess the performance of diagnostic tests or clinical guideline implementation, few evaluate TB data quality, and we are unaware of broader surveys of the impact of poor quality data. We surveyed TB researchers and care providers in high TB burden countries and present those results in the context of our clinical and research experiences. We propose a multilevel approach to improve systems for the benefit of patients, public health programs, and biomedical research.

METHODS

Our experiences are primarily from South Africa, which has a disproportionately high TB burden despite its wealth relative to other high TB burden countries. To synthesize experiences across a range of settings, we conducted a survey of TB care providers and researchers on their experiences with data systems in high TB burden countries.[1] We searched PubMed for TB-related publications from the WHO-designated 30 high TB burden countries[1] by country of institutional affiliation and/or conduct of research between September 2011 and September 2016. The Supplementary Data includes search terms and the number of individuals identified by search results per country (Supplementary Table S1).

We emailed REDCap[4] surveys to at least 20 of the most frequently published authors of TB-related English language publications. We included those whose email addresses were available by PubMed, publication, or institutional website searches. We sent four follow-up email reminders as needed. For countries from which no invitees responded, we sent additional invitations to other co-authors in an attempt to optimize representation from high TB burden countries. We tabulated the survey results and reviewed the free-text comments. We used survey results and consultation with colleagues involved in TB clinical care and research to develop a framework for improving TB data systems.

RESULTS

Survey respondents

We sent surveys to 697 individuals and received responses from 135 (19%) individuals. Forty-three were involved in TB clinical care in the previous 10 years, 125 were involved in research in a WHO high TB burden country in the previous 10 years, and 42 did both (Figure 1). Supplementary Table S2 provides further respondent details.

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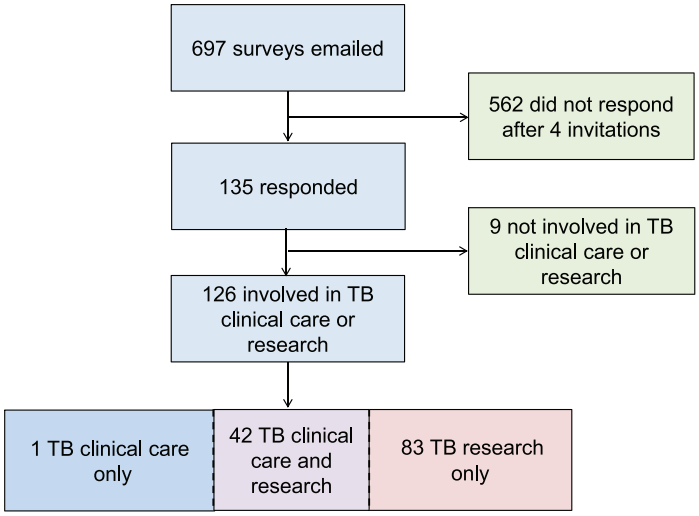

FIGURE 1 Flow diagram of survey distribution and responses. TB = tuberculosis.

Responses regarding clinical care

When asked to name the single most important data-related barrier to excellent TB care, most respondents identified unreliable data linkage among clinics, hospitals, and laboratories (17/43, 40%), followed by lack of expertise for managing or retrieving data (10/43, 23%), lack of a reliable unique patient identifier (5/43, 12%), incomplete data (5/43, 12%), and unreliable data (3/43, 7%) (Supplementary Table S3). Furthermore, 20/43 (47%) of the respondents stated that errors in linking programmatic data across information systems had led to errors in patient care, while 15/43 (35%) cited incorrect matching of unique patient information as leading to similar errors.

Responses regarding research

Over one half of the researchers who responded reported that data limitations had hindered research advances. Within the domain of information systems, researchers identified incomplete data (38/125, 30%), unreliable data linkage (27/125, 22%), and lack of a reliable unique patient identifier (26/125, 21%) as the top three most important research-related barriers (Supplementary Table S4).

With regard to unreliable data linkage and unique patient identifiers, 73/125 (58%) respondents involved in research had observed incorrect patient matching, and 32/125 (26%) reported that patient matching errors caused significant problems or delays in research. Several respondents noted that poor data linkages from laboratories to treatment facilities caused delays in receiving critical test results, resulting in delayed or incorrect treatment. Furthermore, respondents noted that patients who are transferred to different facilities often do not bring their records with them, which can be difficult to recover from referring facilities. Table 1 provides additional examples of patient care errors due to data system limitations drawn from our experience with consequences that included prolonged potential for TB transmission, side effects such as deafness, and incorrect treatment.

The use of a medical record number as a unique identifier did not always mitigate errors related to data linkage; of the researchers who reported exclusive use of a unique identifier at a health facility or laboratory (rather than methods such as patient name and date of birth), 28% noted matching errors with adverse consequences (e.g., persistent duplications, difficulty following patients through the care cascade). When asked who was responsible for verifying whether patients have been previously assigned a unique identifier, 74% of researchers did not respond. The complete survey results can be viewed in the Supplementary Data (Supplementary Tables S2–S4).

Framework for tuberculosis data

Based on the survey results and our experience, we developed a framework for understanding and addressing TB-related data concerns. Figure 2 shows the levels of TB data systems integration according to their potential programmatic scale and impact and the anticipated general ease of implementation. Figure 3 shows how systems that reliably identify and distinguish each patient permit tracing individuals from screening to treatment completion and disease recurrence. Data fields that should be captured in routine TB data systems may vary per setting, but Supplementary Table S5 includes important data fields based on our survey and experience.

DISCUSSION

The survey respondents highlighted the urgent need to strengthen TB data systems. We discuss the themes that emerged from the survey and from our experience below.

The fundamental challenge of patient identification

Reliable identification of a patient's relevant clinical history, whether at one or more sites, is critical for individual care, public health, and research purposes (Figure 2). Correct patient identification can occur

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TABLE 1 Examples of errors in patient care related to data limitations reported by clinicians in Western Cape Province, South Africa. A hypothetical example demonstrates the positive impact of improved data systems

Real-world examples arising from limited data systems
While evaluating patient outcomes in a densely populated informal settlement near Cape Town, South Africa, care providers found that one patient had been assigned more than three medical record numbers in the same care system and seven laboratory registration numbers due to inaccurate capture of personal information. The duplications likely occurred due to varied spellings and ordering of first names and surnames. It was then administratively easier to create a new identity number in the systems rather than check in detail for existing numbers. The errors were only noticed when an epidemiologist took the time late in the patient's care to figure out the patient's entire TB-related history
A female aged 18 years was diagnosed with rifampicin-resistant TB using Xpert® MTB/RIF and started on what was, at the time, the standard MDR-TB treatment regimen that included kanamycin. An audiogram reported hearing loss, so kanamycin was stopped without plans to restart it. She was subsequently admitted to the district hospital, where her previous TB laboratory results were found in the laboratory database, but her treatment records were not identified. Based on her Xpert results, she was started again on a regimen including kanamycin, and subsequently developed deafness. Her initial MDR-TB treatment records were later found under a different medical folder number. If the doctors at the district hospital had all treatment records available under a single medical record number, irreversible hearing loss could have been prevented
A male patient aged 24 years undergoing treatment for MDR-TB at a TB clinic was admitted emergently over a weekend to a nearby hospital intensive care unit for pneumonia. The patient told the doctor in the hospital that he had been previously cured of drug-susceptible TB, but did not inform the doctor that he had recently started MDR-TB treatment. The patient had multiple medical record numbers, and his recently positive sputum results were listed under a different medical record number than the one available to the hospital doctor. Furthermore, the doctor did not have access to the TB clinic records and so was not aware that the patient still posed an infectious risk to others in the hospital. Three additional patients (including a baby) in the closed ward were subsequently exposed to MDR-TB. When the patient did not improve clinically after several days, hospital staff started calling local clinics. The clinic staff who answered the call from the hospital recognized his name, and his MDR-TB treatment records were identified. If the patient had not had duplicate medical record numbers and if his TB treatment details had been linked and available to the hospital doctors, the interruption of the patient's treatment and exposure of other patients could have been avoided
A hypothetical example from a setting with strengthened data systems, and how these improvements can positively impact different domains
A recent migrant is screened for symptoms and tested for TB. He thinks he had a TB diagnosis before but is unsure if it was drug-resistant. His latest Xpert is positive for rifampicin-resistant *Mycobacterium tuberculosis*. By scanning his unique patient identifier, the clinical provider learns that the patient was on MDR-TB treatment a year ago, but subsequently recorded as lost to follow-up. Therefore, the clinical provider requests second-line drug susceptibility testing, and results demonstrate pre-XDR-TB. Based on this, and his prior exposure to pyrazinamide and ethambutol (documented in linked records), he is started on an individualized regimen containing bedaquiline. In a few months, he plans to return home, where his family can support him. The clinic in his hometown is able to import his recent history easily and his treatment can continue uninterrupted
Patient care
The patient's unique identifier ensures that his records are complete
The patient's records are linked across compatible systems that allow TB care providers in different regions access to previous treatment and laboratory records
Optimal laboratory testing and treatment regimens can be selected without unnecessary delays or duplication of efforts
Public health
The patient's movement is able to be reported (allows resource allocation)
The patient's return to care after being considered lost to follow up is identified (ensures appropriate surveillance reporting)
Optimal use of healthcare resources (expedites program evaluation)
Research
Programmatic data can be used due to correctly linked laboratory and treatment data across a region over time
Research involving TB transmission, outcomes, drug resistance, and process evaluation can potentially be conducted

TB = tuberculosis; MDR-TB = multidrug-resistant tuberculosis; XDR-TB = extensively drug-resistant tuberculosis.

through consistent use of information such as names and date of birth, or through a properly assigned unique patient identifier such as a clinic medical record number or a national health identifier. As suggested by our survey, problems with record duplication and incorrect linkage may persist if unique identifiers are not carefully assigned. Although unique patient identification is critical, it is not a panacea.

The WHO and the Joint United Nations Programme on HIV/AIDS (UNAIDS) provide detailed guidance for the implementation of national health identifiers, including in resource-limited countries.[5,6] In countries where a national health identifier is not feasible, a commitment to high-quality data capture that informs a standardized approach to TB patient identification at all points of contact forms the basis of reliable data linkages. Ensuring the reliability of local data with consistent monitoring, evaluation, and planning should be prioritized in all settings.[7]

Biometric data from fingerprints, iris, palm, face, or voice recognition can mitigate the need for patients to present an identification card, remember an identification number, or provide consistent identifying information. A platform using fingerprint recognition on tablets was implemented in a rural setting in Uganda.[8] This provided health workers with immediate feedback regarding treatment adherence and led to improvements in loss to follow-up and patient outcomes. The optimal biometric modality in high-burden populations needs further study with respect to cost, scalability, and data storage and retrieval processes, as well as security, ethics, and stigma.[9]

Access to patient data at a health facility

Providers ideally have access to an individual's medical history when diagnosing and treating TB (Figure 2). Individuals are at times assigned multiple different medical record numbers within the same system, whether at a clinic, hospital, laboratory, or in a TB register (Table 1). Single-site patient identification errors are prone to occur in high-burden settings, particularly when workers lack resources or are not adequately trained in the importance of accurate data capture. Other factors, such as illegible handwriting, keystroke errors in electronic records, and omission of data fields are broadly applicable (Table 2). Since many errors occur at patient registration, emphasis on improving systematic patient

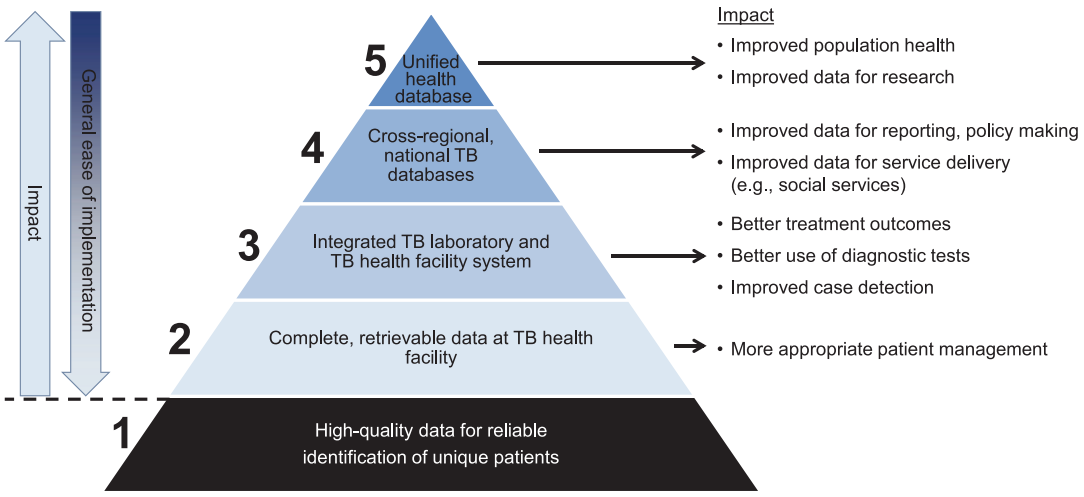

FIGURE 2 Multi-level approach to addressing data systems limitations for TB patient care. Levels are organized according to potential programmatic impact (most impactful at top) and anticipated general ease of implementation (most easily implemented at bottom). Ensuring high-quality data for the reliable identification of individuals for long-term TB care (Level 1) is a critical foundation for improving data systems. Optimized patient care relies on high quality, complete data entry at the point of service (Level 2), which links to other points of service including TB clinics, hospitals, laboratories, and pharmacies (Level 3). Individual patient care data then feed into sub-regional, regional, national, and even supranational databases (Level 4) and can be used to populate interoperable health data on TB, HIV, and non-communicable diseases (Level 5). TB = tuberculosis; HIV = human immunodeficiency virus.

identification strategies at registration would help minimize duplication of patient records and false linking of data (Table 3).[10]

The WHO has provided guidance for standardized recording and reporting of TB data for decades, with updates, tools, and technical recommendations for data quality assessments that can be implemented at health facilities.[11–14] These recommendations are primarily concerned with improved data reporting, but further guidance for establishing and maintaining high-quality data for clinical care and research may be beneficial. Furthermore, factors such as data validation, supervision of staff, and monitoring of data systems rely on funding, availability, and program prioritization of data quality. Data validation should consist of checks for internal consistency, completeness of essential fields, and verification of correctly linked data. Supervision should include demonstration of support for data quality assurance at all levels, including from TB program administrators, and involve appropriate training and supervision of protected time for data capture and data quality work. Resources should be allocated for installation and maintenance of relevant monitoring systems that routinely assess whether reported TB cases at the program level are consistent with individual patient data, patterns of data omissions and duplications, and gaps in the program diagnostic and treatment cascades.

Integrated tuberculosis laboratory and health facility data systems

Health care facilities, laboratories, pharmacies, and registries ideally are integrated to allow immediate and consistent updates to patient information accessible at the point of care (Figure 2). Data systems that leverage standardized, automated technologies or procedures and ensure compatible data formats will minimize linkage errors, thereby contributing to better patient care and outcomes while eliminating wasted resources on duplicate tests. Supplementary Table S6 lists several factors that contribute to data errors between sites, and potential solutions. Most patient data sources represent 'silos' of information; they are either intrinsically limited to a single site (e.g., paper charts at a clinic), or they have not been designed to link with others. Table 1 describes the ideal components of a data system to support TB patient care.

Population migration is a particularly challenging aspect of data systems for TB. Substantial movement occurs in TB-endemic regions due to employment opportunities, political instability, family visits, and cultural customs.[15,16] Patients may also present to different treatment facilities within the same region due to transportation difficulties, stigma associated with the diagnosis of TB, or perceptions of care at a facility.[17]

Electronic information systems that can be monitored and evaluated for internal data quality and linkage with other systems are invaluable for the longitudinal care of TB patients.[18–20] For example, the Global Laboratory Initiative provides guidance for infrastructure development linking diagnostic information to TB programs, potentially allowing seamless and immediate transfer of laboratory results with care providers and electronic registers, along with capacity for data quality monitoring.[21]

Cross-regional and national databases

Reliably and immediately linked laboratory and TB treatment data can be used to populate registers that inform targeted interventions at programmatic levels (Figure 2). Nationally implemented electronic TB treatment registers in South Africa provide opportunities for tracking patients, but still face challenges related to data integrity. For example, only 62% of children with culture-confirmed TB at one referral hospital in South Africa from 2007 to 2009 were registered in the provincial register.[22] Incomplete, duplicate, or incorrect patient data can introduce bias and misrepresent gaps, leading to disordered priorities, misdirected resources, and ultimately, adverse patient outcomes.[23,24]

Data errors can lead to the over- or under-reporting of TB data, which may affect local or national results and global estimates of disease. For example, TB deaths recorded in surveillance differed

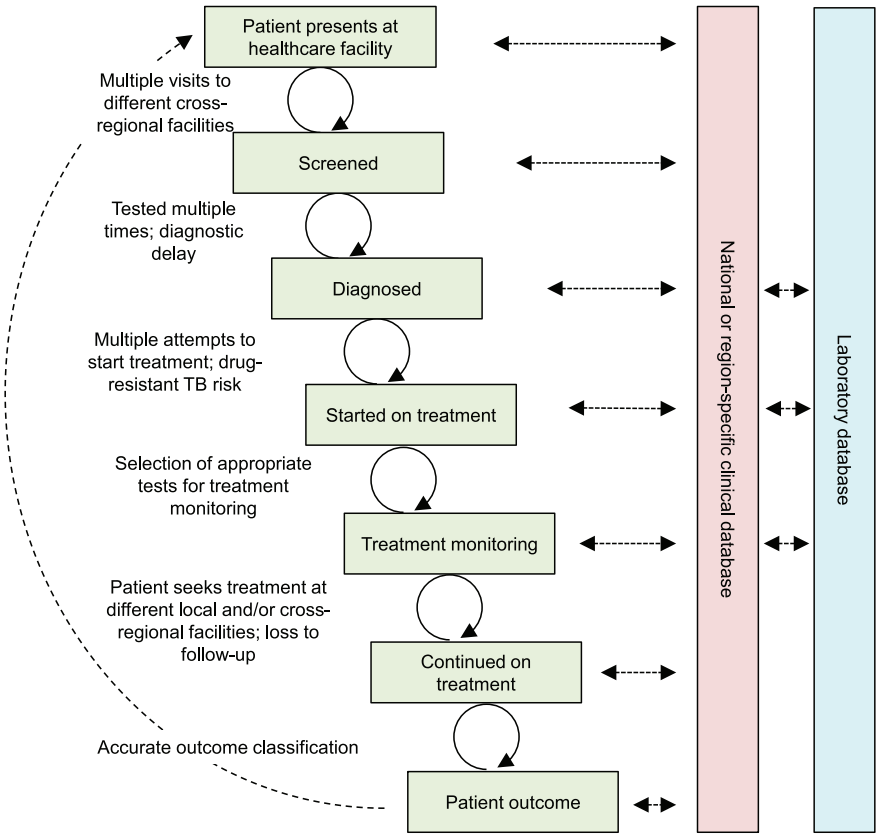

FIGURE 3 Example of TB patient flow and linked information systems from presentation to a health-care facility to outcome after treatment. The straight arrows represent information links, each of which represents opportunities for providing excellent care or liabilities for errors in data entry, patient identification, and linkage. Note that patients can present at different facilities at each step along the pathway. The curved gray arrow denotes that patients can have multiple episodes of care for TB. TB = tuberculosis.

substantially from vital registration systems in England and Wales, highlighting the need for improved data capture for national resource allocation.[24]

Unified health databases across multiple diseases

Interoperable healthcare data systems that extend beyond TB to include regionally significant diseases provide opportunities for streamlined care, tailored public health interventions, and broad population health assessments (Figure 2). With growing interest in comorbidities (e.g., human immunodeficiency virus [HIV] infection, diabetes), unified data systems could facilitate large-scale programmatic planning and research through health information exchange.[25,26]

In South Africa, a provincial health information exchange is being implemented to provide bi-directional transfer of information and immediate access to individual patient and programmatic data.[27] Such approaches for integration of health services may be costly and complicated and require context-specific assessments of effectiveness.[28]

If overall healthcare data systems integration is not feasible in high-burden settings, there may still be opportunities for linking TB data systems to those of other highly relevant diseases.[29] Many of the same data limitations that plague TB also affect HIV care,[30] and investing in integrated TB-HIV data systems might improve patient monitoring in regions with high rates of HIV co-infection.

Research is critical for improving patient care and public health practice. When patients' treatment history and laboratory results are not longitudinally linked, there is an absence of data flow between information systems and facilities (Figure 3), and critical study outcomes such as TB recurrence, acquisition of resistance, or timing of culture conversion may not be captured accurately. For example, when South Africa introduced early bedaquiline access, some pilot sites maintained parallel data sets because existing drug-resistant TB registry data had severe backlogs in data entry and bedaquiline-related data fields were unavailable. On the other hand, programs such as the Structured Operational Research and Training Initiative (SORT IT) have been successful in building capacity for policy-changing operational research while building bridges between TB program staff and researchers.[31] The use of programmatic data for research on the implementation of new technologies and drugs, such as Xpert® MTB/RIF (Cepheid, Sunnyvale, CA, USA) for TB diagnosis, can provide invaluable guidance to other adopting countries.[32,33]

A way forward

To develop integrated systems with reliable patient data, stakeholders across disciplines urgently need to invest resources and coordinate efforts. Funding for data systems improvement is not typically prioritized but is essential. Focused funding calls for sustainable data systems improvements, performance incentives for

TABLE 2 Factors that contribute to data errors within a site or system, with examples and potential solutions. Many errors, including assignment of multiple incomplete patient records to a single patient and allocation of more than one patient's data to a single medical record number occur at registration. Poor data collection at point of care is thereafter carried forward across linked systems and registries and is much easier to prevent or correct at entry than downstream

Factors	Examples	Potential short-term solutions	Potential long-term solutions
Registration information entry errors	Staff misunderstand spelling or order of patient names, birth date, address Patients provide inconsistent name spelling or order, birth date, address, identification number Staff not familiar with patient name pronunciation/spellings or local customary naming conventions (especially cross-cultural) Data entry or transcription errors	Standardized patient registration protocols that account for cultural context of the region (e.g., include both married name and maiden name in identifiers searched at registration) See Table 3 for other solutions	Create or use existing programs that use matching systems based on multiple patient identifiers and provide staff immediate results of partially matching previously registered patients if a perfect match is not found and a mechanism for confirming and merging probable matches Implement unique patient identifiers such as identification number or biometric identifiers Foster an environment that facilitates and values error reporting instead of punitive measures for error reporting or poor outcomes
High patient or specimen volume	Not enough staff time to verify if patient entered in system previously Incomplete data fields	See Table 3 Flags for mandatory data entry fields	New and improved use of existing technologies for efficient TB patient or TB laboratory sample registration (e.g., barcodes, biometrics)
Insufficient staffing or skills	Data capture and quality assurance roles not prioritized Staff given responsibility for data without adequate training or support Poor understanding of importance of identifiers and data	Education and training Support and incentives for excellent patient registration, data entry, data quality assurance practices	New and refresher curricula for staff: importance of data integrity
Limited data support	Limited data entry equipment or technical support Unreliable internet	Purchase more equipment Flexible work hours for more computer access	Funding of data entry and data support personnel Training program managers about data quality, necessity of resources for data integrity
Patient health literacy	Patients may not remember exact identification information or previous treatment details	Emphasize patient education within treatment model, empower TB patients to be stewards of their care Assign patients specific staff members for longitudinal care	Community engagement and TB education campaigns Implement a system of patient-held clinical notes, to be used at every health service interaction Biometric identification
Intentional data errors	Patients falsify identifiers due to stigma, fear of identification Staff alter outcomes due to performance incentives or administrative expectations, demands, or threats	Include performance incentives for staff to capture high data quality	Foster a compassionate healthcare environment that educates healthcare workers on ways to avoid stigmatizing patients, e.g., 'values clarification' workshops Encourage a culture of transparency and error reporting

TB = tuberculosis.

TABLE 3 Strategies for registering TB patients without introducing errors leading to duplication of records or patient misidentification[10,34]

Observe and evaluate current patient registration systems and flow to determine site-specific performance and sources of patient registration errors
Develop a standardized approach for patient registration which makes assignment of a new medical record number an option of last resort after asking patients if they have been registered at the site previously and iterative searches for previous patient records using multiple variations of several identifiers
Train all individuals responsible for registering patients in standard procedures with initial and refresher sessions, emphasize the importance of correct patient registration for patient care, and assess competency
Review patient registration performance regularly (can be daily), and provide performance feedback to individuals regarding data entry errors, including duplications
Use technology to optimize searches for previous patients, including customized probabilistic matching software, to prompt possible matches to master patient index and incorporation of patient photographs into medical record for additional verification
Provide access to information technology support staff
Perform regular quality control of the patient registration process in conjunction with evaluation of master patient data for the facility
Ensure that managers and staff know who is responsible for data quality, including assignment and verification of medical record numbers/unique health identifiers

TB = tuberculosis.

TB programs and staff, and motivation for companies to develop cost-effective and scalable technologies should be pursued.

Our survey had important limitations, including a low response rate and lack of representation from many TB control programs. We did not specifically target TB program workers, although many TB researchers are actively engaged in programmatic work. Participation of TB program staff and managers to assess weaknesses and implement improvements is essential and will complement the recommendations made here.

CONCLUSION

TB data systems have critical weaknesses in many high-burden settings. Unless approaches to improve such systems are implemented now, preventable errors in patient care will continue. Furthermore, program and policy decisions will be supplied with inaccurate information that could jeopardize the efficient use of funds, and answers to important research questions will remain inaccessible. Current efforts to improve data limitations require substantially increased support from stakeholders, clear strategies for performance evaluation, and the use of frameworks for the optimization of patient care based on these data systems improvements.

References

1 World Health Organization. Global tuberculosis report, 2018. WHO/CDS/TB/2018.20. Geneva, Switzerland: WHO, 2018. http://apps.who.int/iris/bitstream/handle/10665/274453/9789241565646-eng.pdf?ua=1 Accessed September 2019.
2 World Health Organization. Implementing the end TB strategy: the essentials. WHO/HTM/TB/2015.31. Geneva, Switzerland: WHO, 2015. http://www.who.int/tb/publications/2015/end_tb_essential.pdf?ua=1 Accessed September 2019.
3 World Health Organization. Digital health for the End TB strategy: an agenda for action. WHO/HTM/TB/2015.21. Geneva, Switzerland: WHO, 2015. http://www.who.int/tb/areas-of-work/digital-health/Digital_health_EndTBstrategy.pdf?ua=1. Accessed September 2019.
4 Harris P A, Taylor R, Thielke R, Payne J, Gonzalez N, Conde J G. Research electronic data capture (REDCap)–a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009; 42(2): 377–381.
5 Joint United Nations Programme on HIV/AIDS. Considerations and Guidance for Countries Adopting National Health Identifiers. Geneva, Switzerland: UNAIDS, 2014. http://www.unaids.org/sites/default/files/media_asset/JC2640_nationalhealthidentifiers_en.pdf Accessed September 2019.
6 Beck E J, Shields J M, Tanna G, et al. Developing and implementing national health identifiers in resource limited countries: why, what, who, when and how? Glob Health Action 2018; 11(1): 1440782.
7 Theron G, Jenkins H E, Cobelens F, et al. Data for action: collection and use of local data to end tuberculosis. Lancet 2015; 386(10010): 2324–2333.
8 Snidal S J, Barnard G, Atuhairwe E, Ben Amor Y. Use of eCompliance, an innovative biometric system for monitoring of tuberculosis treatment in rural Uganda. Am J Trop Med Hyg 2015; 92(6): 1271–1279.
9 Kavanagh M, Baral S, Milanga M, Sugarman J. Biometrics and public health surveillance in criminalised and key populations: policy, ethics, and human rights considerations. Lancet HIV 2019; 6(1): e51–e59.
10 Just B H, Marc D, Munns M, Sandefer R. Why Patient matching is a challenge: research on master patient index (MPI) data discrepancies in key identifying fields. Perspect Health Inf Manag 2016; 13: 1e.
11 World Health Organization. Manual on use of routine data quality assessment (RDQA) tool for TB monitoring. WHO/HTM/TB/2011.1. Geneva, Switzerland: WHO, 2011. http://apps.who.int/iris/bitstream/handle/10665/44545/9789241501248_eng.pdf?sequence=1&isAllowed = Accessed September 2019.
12 World Health Organization. Definitions and reporting framework for tuberculosis–2013 revision. WHO/HTM/TB/2013.2. Geneva, Switzerland: WHO, 2013. http://apps.who.int/iris/bitstream/10665/79199/1/9789241505345_eng.pdf Accessed September 2019.
13 World Health Organization. Standards and benchmarks for tuberculosis surveillance and vital registration systems: checklist and user guide. WHO/HTM/TB/2014.02. Geneva, Switzerland: WHO, 2014. http://apps.who.int/iris/bitstream/10665/112673/1/9789241506724_eng.pdf?ua=1 Accessed September 2019.
14 World Health Organization. Understanding and using tuberculosis data. WHO/HTM/TB/2014.09. http://apps.who.int/iris/bitstream/handle/10665/129942/9789241548786_eng.pdf?sequence=1 Accessed September 2019.
15 Rees D, Murray J, Nelson G, Sonnenberg P. Oscillating migration and the epidemics of silicosis, tuberculosis, and HIV infection in South African gold miners. Am J Ind Med 2010; 53(4): 398–404.
16 Bocquier P, Collinson M A, Clark S J, Gerritsen A A, Kahn K, TollMan S M. Ubiquitous burden: the contribution of migration to AIDS and Tuberculosis mortality in rural South Africa. Etude Popul Afr 2014; 28(1): 691–701.
17 Bekker S B. Migration Study in the Western Cape 2001. Western Cape Province, South Africa: Provincial Government of the Western Cape, 2002. https://www.westerncape.gov.za/text/2003/migration_study_2001_3_main_rep.pdfAccessed September 2019.
18 OpenMRS. Open Medical Record System. Carmel, IN, USA: OpenMRS, 2017. http://openmrs.org Accessed August 2017.
19 Were M C, Emenyonu N, Achieng M, et al. Evaluating a scalable model for implementing electronic health records in resource-limited settings. J Am Med Inform Assoc 2010; 17(3): 237–244.
20 Blaya J A, Shin S S, Yale G, et al. Electronic laboratory system reduces errors in National Tuberculosis Program: a cluster randomized controlled trial. Int J Tuberc Lung Dis 2010; 14(8): 1009–1015.
21 Global Laboratory Initiative. GLI Quick Guide to TB Diagnostics Connectivity Solutions. Grand-Saconnex, Switzerland: Stop TB Partnership, 2016. http://stoptb.org/wg/gli/assets/documents/gli_connectivity_guide.pdf Accessed September 2019.
22 du Preez K, Schaaf H S, Dunbar R, et al. Incomplete registration and reporting of culture-confirmed childhood tuberculosis diagnosed in hospital. Public Health Action 2011; 1(1): 19–24.
23 Harron K, Wade A, Muller-Pebody B, Goldstein H, Gilbert R. Opening the black box of record linkage. J Epidemiol Community Health 2012; 66(12): 1198.
24 Lalor M K, Mohiyuddin T, Uddin T, Thomas H L, Lipman M, Campbell C N J. The challenge of estimating tuberculosis mortality accurately in England and Wales. Int J Tuberc Lung Dis 2018; 22(5): 572–578.
25 Oni T, Stoever K, Wilkinson R J. Tuberculosis, HIV, and type 2 diabetes mellitus: a neglected priority. Lancet Respir Med 2013; 1(5): 356–358.
26 Williams C, Mostashari F, Mertz K, Hogin E, Atwal P. From the Office of the National Coordinator: the strategy for advancing the exchange of health information. Health Aff (Millwood) 2012; 31(3): 527–536.
27 Heekes A, Tiffin N, Dane P, et al. Self-enrolment antenatal health promotion data as an adjunct to maternal clinical information systems in the Western Cape Province of South Africa. BMJ Global Health 2018; 3(Suppl 2): e000565.
28 Shigayeva A, Atun R, McKee M, Coker R. Health systems, communicable diseases and integration. Health Policy Plan 2010; 25(Suppl 1): i4–i20.
29 Dusetzina S B, Tyree S, Meyer A M, Meyer A, Green L, Carpenter W R. Linking data for health services research: a framework and instructional guide. Report no 14-EHC033-EF. AHRQ Methods for Effective Health Care 2014. Rockville, MD, USA: US Agency for Healthcare Research and Quality. https://www.ncbi.nlm.nih.gov/books/NBK253313/ Accessed September 2019.
30 Clouse K, Vermund S H, Maskew M, et al. Mobility and clinic switching among postpartum women considered lost to HIV Care in South Africa. J Acquir Immun Defic Syndr 2017; 74(4): 383–389.
31 Ramsay A, Harries A D, Zachariah R, et al. The Structured Operational Research and Training Initiative for public health programmes. Public Health Action 2014; 4(2): 79–84.
32 Theron G, Zijenah L, Chanda D, et al. Feasibility, accuracy, and clinical effect of point-of-care Xpert MTB/RIF testing for tuberculosis in primary-care settings in Africa: a multicentre, randomised, controlled trial. Lancet 2014; 383(9915): 424–435.
33 Churchyard G J, Stevens W S, Mametja L D, et al. Xpert MTB/RIF versus sputum microscopy as the initial diagnostic test for tuberculosis: a cluster-randomised trial embedded in South African roll-out of Xpert MTB/RIF. Lancet Glob Health 2015; 3(8): e450–e457.
34 Bittle M J, Charache P, Wassilchalk D M. Registration-associated patient misidentification in an academic medical center: causes and corrections. Jt Comm J Qual Patient Saf 2007; 33(1): 25–33.

Cadre : Le diagnostic et le traitement de la tuberculose (TB) exigent des patients de multiples rencontres avec le système de santé et les différentes parties prenantes qui jouent un rôle dans leur guérison afin de coordonner leurs efforts. Pour que cela se passe au mieux, des données de grande qualité facilement disponibles sont requises. Les systèmes de données visant à faciliter ces liens sont une priorité négligée dont la faiblesse affaiblit intrinsèquement les interventions de lutte contre la TB.
Objectif : Décrire les leçons apprises à partir de l'utilisation des données de programme dans la prise en charge des patients atteints de TB et pour la recherche.
Méthode : Nous avons réalisé une enquête sur les expériences de chercheurs et de cliniciens relatives aux systèmes d'information et élaboré une approche progressive pour examiner les obstacles fréquemment rapportées à une prise en charge de bonne qualité.
Résultats : Des liens non fiables, des données incomplètes, l'absence d'un identifiant unique fiable pour chaque patient et le manque d'expertise en gestion des données ont été les obstacles les plus importants, en termes de données, à une bonne qualité de la prise en charge des patients et de la recherche. Nous proposons la création d'un environnement de prestation des soins de santé qui facilite, priorise et évalue la saisie de données de bonne qualité lors de l'enregistrement du patient ou d'un échantillon biologique.
Conclusion : Une approche intégrée, concentrée sur des données de qualité élevée, centrée sur une identification unique de chaque patient, constituera la base des liens entre systèmes de santé qui réduisent les erreurs de prise en charge des patients, renforcent la surveillance et améliorent la qualité de la recherche basée sur les données du programme.

Marco de referencia: El diagnóstico de la tuberculosis (TB) y su tratamiento exigen contactos múltiples de los pacientes con el sistema de atención de salud y los diferentes interesados directos que intervienen en su curación a fin de coordinar sus esfuerzos. Una coordinación óptima precisa la existencia de datos de gran calidad. El hecho de descuidar la prioridad de los sistemas de datos que facilitan estos vínculos, los debilitan y socava las intervenciones de control de la TB.
Objetivo: Describir las enseñanzas extraídas de la utilización de los datos programáticos en la atención de los pacientes y la investigación en materia de TB.
Método: A partir de una encuesta sobre la experiencia de los investigadores y los proveedores de atención con los sistemas de información, se elaboró un método escalonado con el fin de abordar los obstáculos frecuentes referidos en la prestación de una atención de buena calidad.
Resultados: Los principales obstáculos relacionados con la buena calidad de la atención de salud y la investigación fueron los vínculos poco fiables, los datos incompletos, la falta de un número único seguro de identificación de los pacientes y la incompetencia en la gestión de los datos. Se propone la creación de entornos de prestación de servicios de salud que faciliten, den prioridad y evalúen el ingreso de datos de buena calidad en el momento del registro del paciente o de las muestras.
Conclusión: Un enfoque integrado basado en la calidad de los datos, alrededor de un número de identificación único de los pacientes, constituirá el cimiento de vínculos entre sistemas de salud que promueven la disminución de los errores de manejo de los pacientes, el refuerzo de la vigilancia y la promoción de la calidad de la investigación basada en los datos programáticos.

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